

# **COMMUNITY IMMUNIZATION REGISTRIES MANUAL**

## **CHAPTER I: PLANNING\***

**Prepared by**

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March 14, 1997

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## INTRODUCTION TO CHAPTER I

The nation is making considerable progress towards reaching the goal of ensuring that at least 90% of our 12- to 23-month-old children are fully up-to-date for their recommended immunizations by the year 2000. However, to achieve this goal new approaches are needed to overcome deficiencies in current immunization information handling practices. These deficiencies include: (1) Incomplete records due to fragmentation of health care delivery. This is often seen in the movement of “at-risk” children from public providers to Medicaid managed care. Such movement may hinder the ability of providers and parents to assess immunization needs as well as the ability of third-party payers to validate the quality of services their customers receive. (2) Antiquated methods resulting in large and cumbersome files of paper records. Such files may not allow rapid access to immunization histories, even in one physical location. (3) Errors or difficulties in assessing immunization needs due to the increasing complexity and continually changing nature of the immunization schedule.

To sustain high coverage rates for future generations, current efforts should be aimed at permanently resolving these deficiencies. Immunization registries, or electronic immunization information systems can meet this need. A stable infrastructure based on electronic systems (immunization registries) would help parents by providing a timely, accurate, and simple means to remind them of immunizations due. It would assist providers by incorporating immunization information as an accessible and integral component of patient data. Minimal time would be needed to review records and prepare reports to meet the requirements for school attendance. Assistance to public health officials would be provided in the form of an assessment tool to rapidly and continually monitor immunization coverage rates and identify special needs that may require a concentration of resources.

To achieve their objectives, immunization registries must maintain timely and complete immunization records for the children residing in their catchment areas,\*\* including entering children into the registry as soon as possible after birth. Technology alone is not the answer to these needs. The planning, building, and running of immunization registries requires concerted and sustained involvement of public health staff, parents, providers, health plans, insurers, professional associations, civic and service organizations, elected representatives, government officials, and businesses. Ideally, all should lend their support to ensure that the needs are appropriately met. In many cases, a community rather than a state effort will be

more successful, since local problems and needs can more easily be taken into account. This manual presents information to assist good planning at either the community or state level,

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\*\*Editor’s note: Throughout this manual, immunization registries are described as including all children in a specific geographic (i.e., “catchment”) area. Nevertheless, many of the concepts underlying registries apply equally well to computerized information systems containing detailed immunization information on many children in disparate geographic areas, as a large multi-state managed care organization might do. In fact, some might consider that the term “immunization registry” could properly be applied to such systems.

a pre-requisite for successful development of immunization registries.

Establishing a successful immunization registry requires a working group of committed individuals, including “visionaries,” or persons skilled in planning, to promote the concept and lead development of an immunization registry for their community. The “visionaries” needed for this task include individuals who are experts in immunization or maternal and child health care and others who are able to encourage influential people to support this cause. Once the required people or groups are identified, formal planning can begin. It is suggested this be done in several phases: 1. preliminary analysis of needs and resources; 2. development of formal partnerships that collectively set the scope and objectives for the registry; 3. in-depth planning addressing important technical issues. Issues will include considerations that affect overall design of the registry data base and telecommunications systems to be used, promotion of the registry, and securing adequate resource. In these last stages it may be helpful to communicate the specific problems that the registry can solve or mitigate for your community, some of which are suggested below:

**Problems an Immunization Information Registry can address:**

- o Incompleteness or errors in immunization records when shots are given at multiple sites.
- o Unnecessar re-immunization due to incomplete records.
- o Difficulty in assessing a child's immunization needs due to the increasing complexity of the immunization schedule.
- o Keeping current with new recommendations.
- o Assembling and reviewing voluminous paper records to determine a child's medical history.
- o Lack of immunization records maintained and/or brought by parents.
- o Providers unaware of the numbers of their patients who are under-immunized.
- o Difficulty of assessing immunization coverage levels without conducting expensive surveys.
- o Difficulty of parents keeping track of when their children's immunizations are due
- o Difficulty of third-party payers to validate the quality of service provided their customers.

# **Section 1: PRELIMINARY ANALYSIS OF NEEDS AND RESOURCES**

## **DETERMINING IMMUNIZATION NEEDS**

The first step in planning an immunization registry is analyzing the community needs. Included in the analysis should be a review of available technology options, an estimate of costs, and an identification of potential resources. A careful analysis will bring to light any problems that will need to be overcome to successfully establish the registry. During this phase sharing the vision of the registry in the community with those whom it will benefit is advisable.

Needs assessments involve defining the population to be served, determining immunization coverage levels, identifying any special “pockets of need,” assessing barriers to immunization, and describing the infrastructure of the health care delivery system(s) in the catchment area. One such example follows.

In **San Diego County** a combination of existing data and new data collected for their planning phase was used. Existing data were from a 1994 retrospective survey in kindergartens, that indicated that about 70% of San Diego County's two-year-old children were up-to-date on their immunizations. Over a one-year period, additional data were collected by meeting with physicians, computer experts, community service organizations, and parents from throughout the county. These meetings were held to discuss obstacles to immunization and to gather input for the design of a computerized monitoring and recall application. Focus groups were assembled with parents and interviews conducted with key informants to address issues and concerns about the immunization registry.

## **LOOKING AT TECHNOLOGY**

Decisions on information technology must be linked to decisions on the functional capabilities the system will need (see Chapter III) and may be “high-tech” or “low-tech” accordingly. In fact, many registries currently accommodate diverse levels of technology, at least until all users reach technological parity. Local policy issues that need to be addressed concerning software and hardware include the following:

- o How will large and small private providers (hospital-based, managed care clinics, or individual providers) be connected?

- o Will hardware be provided by a participating agency, leased, or purchased?
- o Is appropriate software currently available? Will it be developed in-house, obtained as shareware, or will it be purchased?
- o What communication links exist in the community (e.g. Community Health Information Networks [CHIN]), and what new ones will need to be established?
- o How will technical support be provided?
- o How will users be trained?
- o What kind of security issues will need to be addressed and how will this be done?
- o What funds are potentially available to start up and maintain the registry?

When evaluating hardware and software packages, consider their flexibility, adaptability for change, capacity for growth, the vendor's reputation, and the level of technical support the vendor offers. Vendors should be responsive in providing system maintenance and be willing to update the system to meet your specific needs. Examples of various levels of technology follow.

**Mississippi** has contracted with a single vendor to develop an integrated, on-line, patient information system operated by the state. The system runs on a mainframe, connecting the public sector clinics via a wide area network. Initially, to provide service for the remaining providers in the private sector, standardized reporting forms will be mailed or faxed to the registry. Their data will be manually entered by registry staff. Private providers will be able to query the registry for immunization information for their clients by calling a toll-free number. Eventually, private providers will be able to access the system via standard computer-telephone modems. They will then be able to view immunization information for their clients and enter their vaccine administration information into the registry.

In **Snohomish and King Counties, Washington** software has been developed to operate under the UNIX operating system on a “host” 32-bit computer, which functions as a server. At user sites, communications software is installed on PCs that connect by modem to the “host” as remote terminals. To solve the problem of printing out reports in providers' offices, the registry computer is programmed to format reports and direct them to the

FAX number of the provider using the system. Other methods such as, local area networks (LAN), wide area networks (WAN), FAX, and touch-tone phone menu options will be developed to connect providers.

In **San Bernardino County, California**, a team developed the database design and application programming. A single vendor was selected for in-house development of a relational database and user interface, using software running on Microsoft's Windows NT operating system. The software provides "user-friendly" screens and portable computers are carried by public health nurses to non-permanent immunization clinic sites. Connectivity for private providers is being established in a variety of ways as in the Snohomish county project.

In **Oregon** the Health Department convened a focus group of physicians to explain its design for a registry. The physicians suggested that the extra time required for them to record immunizations for the registry should be no more than "three seconds." The Oregon registry then developed a bar-code form for providers to use to record each immunization as it is given. Bar-coded stickers, including the I.D. number for that form, define each recommended shot. In order to record the immunization, the correct bar-code must be peeled off from the appropriate space and transferred to a mail-in card, that is sent to the health department where it is machine scanned. Information output to providers will involve Faxback technology and telephone reports.

Further information on these issues are given in the Technology chapter.

## **COSTS AND SUPPORT**

It is desirable to conduct a cost analysis for the registry, including initial development, daily operation, maintenance, and equipment replacement costs. If any doubts exist as to what is entailed, guidance from others familiar with registries should be obtained.

Short-term support, or seed money, may be needed for the initial planning activities, especially as efforts are ongoing to create interest in the project. From the outset, planners should take into account the long term needs for support, including financial, even after the chosen system has been purchased or developed. By prioritizing the steps in setting up the registry and developing a realistic time line and staffing needs, it will be easier to determine the type and amount of support needed at various stages of the process.

Establishing a registry may take five or more years. Planners should allow one year for planning, one to two years for technology selection, development and field testing, and one

to two years for fully implementing the system. The basic staffing required includes a project manager, a community coordinator, a technical systems analyst, and a physician support position. Compiling a list of possible sources of support, both monetary and in-kind, will provide an idea of how sustainable registry support might be.

By emphasizing the benefits of the system, sustainability for the registry eventually may be achieved through contributions from users as well as possible public health funding. An example of how users' contributions were obtained follows.

In **New York State** the Health Department promoted the registry to providers as an aid to the work done in their practices. Many providers, realizing it was to their benefit to support linkages from their office computer to the registry, elected to bear the expense of making their systems compatible with that of the registry.



## **Section 2: PARTNERS, COMMUNITY OBJECTIVES AND OVERSIGHT**

The chances for implementing , sustaining and improving a registry over the long term are improved if, from the outset, it receives committed support from the people who will use it and benefit from it. Involving the community in setting objectives and evaluating progress and results is highly recommended as the registry project proceeds.

### **FORMING COMMUNITY PARTNERSHIPS**

Identifying potential community partners who may become stakeholders is a key step. Different partners will bring different skills and priorities to the planning table. Determine the strengths and interests each potential participant offers and how mutually beneficial arrangements can be developed. When inviting organizations or individuals to join as partners, be careful to choose those whose participation is most likely to be of help to the registry. Once commitments to the goals of the registry are evident, selection of those to invite to participate in an advisory or governing capacity can be arranged. Every effort needs to be made to ensure that the community truly feels involved in the project from the outset. Examples of approaches to developing community partnerships follow:

In **Atlanta, Georgia** during 1993, the public became aware of low immunization levels in neighborhoods in and around the city. To raise these levels, the Carter Center sponsored an initiative under the auspices of The Atlanta Project to make parents aware of their child's immunization levels. Private industry assisted by providing financial and personnel support. As a part of this effort, an immunization registry was developed. As the impetus of The Atlanta Project's drive subsided, a few computer and health care experts were determined to keep the immunization registry intact and to expand its use throughout the metro Atlanta area. Through their efforts, the data base was expanded to include records from 12 participating groups of clinics and hospitals in the two counties closest to the center of Atlanta. The registry now contains records on over 120,000 pre-school children and its oversight comes from a board comprised of representatives from the participating clinical facilities.

In **Cleveland, Ohio** the Urban Pediatrics Group and the Cleveland Department of Public Health initiated their All Kids Count project in 1993. They knew support was needed from a broad spectrum of the community if the registry was to help reach the goal of improving the immunization status of children in the Greater Cleveland area. They wanted to develop a

consortium that was able to cut across institutional barriers throughout the community and unite everyone for a common goal. The Cleveland project initiators made lists of all the potential stakeholders throughout the registry's catchment area. They began to sort those stakeholders into categories by the types of organizations they represented and the possible services or benefits they could bring to the project, along the following lines:

## Categories of organizations considered as community partners in the Cleveland, Ohio Registry

Universities & Schools	Non-governmental Hospitals	Umbrella Organizations	Governmental Organizations	Managed Care Organizations	Health Care Plans
Cleveland State University	St Lukes Medical Center	Rotary International	Cleveland Department of Public Health	Urban Pediatrics Group	University MEDNET
Cleveland Public Schools	Mt Sinai Medical Center	Kiwanis International	Ohio Department of Health	Greater Cleveland Hospital Association	Kaiser Permanente
	University Hospitals of Cleveland	Hadassah	Lakewood Department of Public Health	Cleveland Visiting Nursing Association	Total Health Care
	Mercia Hillcrist Hospital		Cuyahoga County of Health		
	Southwest General Hospital		WIC program		
	Deaconess Hospital				
	Parma Community Hospital				
	Cleveland Clinic Foundation				

## FORMING AN ADVISORY BOARD

Once the community partners are identified it may be desirable to establish a formal relationship among them, such as creating an Advisory Board or even a governing body with fiscal and administrative responsibility. In taking either of these steps it may be helpful to consider whether additional stakeholders should be invited to join the group. Input on this matter should be sought from the stakeholders in the community to be served by the registry. Consider both the benefits such additional members would receive by being members of these bodies and the assets they would bring to the advisory or governing process. An example is shown below for determining who to invite:

### **Benefits to and assets of potential Advisory Board members**

<b>Stakeholder</b>	<b>Stakeholder Benefit(s)</b>	<b>Stakeholder Assets</b>
Elected officials	Shows constituents the official is concerned with their children's health.	Can cut red tape and promote or pass legislation if needed.  Policy Development skills.
Managed Care Organizations (MCOs)	Registry can help MCOs provide a better service and meet HEDIS targets, by adding data on immunizations from outside their own plan: also increases their visibility in the community.	As more states move to Medicaid-Managed Care, MCOs will assume many responsibilities for this population.

### **FORMING A GOVERNANCE BODY**

Developing a governance structure such as a charter and by-laws provides an opportunity to turn stakeholders into partners. While clear leadership is essential, using a “round table” approach to discuss and resolve issues related to registry development promotes the concept that all partners are equally involved. Each partner can receive assurance of his or her place in the process through such means as the development of written agreements, contracts, or memoranda of understanding. Working together in this manner also serves to foster a better understanding of one another's business and mission. Establishing regular meeting times, voting, making decisions, setting roles and responsibilities all serve to help members understand where they fit into the process. Early in the process the governing body needs to determine how many members are needed to make a decision and whether certain decisions can be made only by certain people. It should also be noted that the binding together of like-minded health care professionals tends to lend a degree of political “clout”

to their opinions that they would not otherwise enjoy individually. Give appropriate credit to the efforts of those helping the registry.

One example of the procedures used by the community coalition providing oversight and support for a registry follows:

In **New York City** the Coalition for Immunization Initiatives includes public and private health care providers, provider association representatives, advocates for children, elected officials, and other community leaders. The full coalition has four meetings per year. Four committees also have been established: 1) Executive; 2) Provider; 3) Technical; and 4) Community Outreach. The committees meet on an ad-hoc basis. The Coalition played an integral role in building broad-based support for the registry. The coalition was also the prime mover in getting an amendment passed that authorized the registry to obtain funding from the city and state.

## **DEFINING THE SCOPE OF THE REGISTRY**

As planning begins, one of the first tasks is to establish the desired scope of the registry. Next, confirm the level of support that exists for what is envisaged. A clear mission statement and objectives can define precisely what the registry will do, how it will do it, and for whom it will be done. In setting the scope of the registry, specify the age groups to be included, the geographic area to be covered, the degree and number of services that will be performed, and the numbers and types of providers who will be served.

## **EVALUATION**

A formal evaluation process should be developed during the planning phase. Having a written evaluation plan will keep attention on this aspect, encourage delegation of the assignments to responsible staff, and promote regular reporting to senior management. A good approach to evaluation will help identify problems before serious damage is done. Evaluation will ensure that registry resources are being used in a focused manner to meet the overall program goal of increase immunization coverage. Both process and outcome evaluation procedures will be needed. The following aspects of establishing an evaluation process should be considered to ensure a systematic approach is in place at the outset.

### **Types of activities to monitor**

Criteria for choosing activities to monitor include:

- o Importance: because evaluation is time-consuming, critical aspects should receive priority, such as considering the percentage of any given birth cohort for whom records exist in the data base, and weighing the immunization coverage rates for different sub-populations.
- o Observing or measuring progress: "client satisfaction" is an important indicator of success, but may be harder to measure than an electronic count of the frequency of provider usage each week. Such a record of registry utilization, indicating increase, decrease, or stabilization, may indirectly indicate the usefulness of the system to its users.
- o Frequency of conducting the activity: some activities will require monitoring on a more frequent basis due to the nature of the activity. Because training may be intermittent, assessing user training activities may be less helpful than frequently assessing the operation of a user "help desk".

### **Methods for monitoring**

These methods will require different resources and varying amounts of time:

- o Examination of documents or records, such as protocols or data base entries.
- o Feedback from providers or the public, collected through formal surveys.
- o Automated electronic reports generated on various operational aspects, such as the mean, average, and range of elapsed time between the date of immunization and the date when data is added to the registry records.

### **Frequency of monitoring**

A planned schedule for conducting and reporting evaluations should be set to ensure the task is not overlooked. Different pre-determined intervals can be set for reporting different parameters, usually with a frequency included in the analysis. As noted earlier, some activities lend themselves to monitoring more frequently than do others. Some hypothetical examples are suggested, including:

- o Complaints about connectivity problems should be monitored on a daily basis in

order to quickly detect events of significance that may negatively impact upon the system or to detect whether overloading of the system occurs at certain times or on certain days of the week.

- o Weekly assessment should be made of the number of immunizations reported by each provider site. A decrease may reflect decreased commitment to report to the registry.
- o Monthly assessments should be made of expenditures and income vs forecasts as well as the total number of public and private provider sites connected. By so doing, it is possible to track whether the project is within budget.
- o The numbers of reminder or recall immunization notifications provided might also be assessed as an indicator of the true usefulness of the system in expanding immunization coverage.
- o In-depth quarterly assessments should be made of immunization coverage levels by provider site and population cohort with considerations given to the implications for the major organizations participating.
- o Semi-annual reviews are needed of the “lessons learned,” actions still pending, and prioritizing future changes or plans.
- o Yearly assessment should be made of all policies and procedures and whether existing equipment will continue to support the initial program objectives. An annual survey of providers and the public might also add to the overall knowledge of customer satisfaction.

### **Persons responsible**

Assessment duties may be assigned to an individual or a small number of people. They should be staff or peers who will also benefit from having the data, will know how to analyze and use it, and who have the technical skills to collect the data themselves.

A sample worksheet for use in planning and performing evaluations follows. See Chapter IV, **OPERATIONS**, for further information.

### **SAMPLE WORKSHEET FOR PLANNING & CONDUCTING EVALUATIONS**

**Sample outcome or impact objective:** "By January 1, 1998, 30% of all children <1 yr, and

60% of all children < 1yr enrolled in WIC, will have immunization records in the registry"

Indicator	Method/Source of Data	Frequency (how often to collect indicator data)	Person(s) responsible
Total number of children 2-12 months old w/ immunization data in registry	Registry database	Monthly	Database manager
Total number of children 2-12 months old	Vital statistics registrar	Monthly	Community coordinator
Total number of children 2-12 months old, enrolled in WIC	USDA/WIC	Monthly	Community coordinator
Total number of children 2-12 months old, enrolled in WIC, in registry	Registry database	Monthly	Database manager

The evaluation process, while requiring time and the use of precious resources, nevertheless, is critical in achieving or ultimate goal: **That at least 90% of 12- to 23-month-old children be fully up-to-date for their recommended immunizations by the year 2000.**

### **Section 3: IN DEPTH COMMUNITY PLANNING AND PROMOTION**

Setting the scope and objectives of the registry provides a basis for agreeing on the appropriate technological methods to be applied and precisely establishing the resources that must be secured. When it has been decided what the registry is intended to "deliver," and the means by which it will be achieved, it then becomes possible to draw up plans for promoting the registry to users and to the community. Many policy decisions will need to be made in order to reach this point. But, even after the scope and objectives have been agreed upon, many questions remain. These include how to ensure the quality of data, how to implement policies and procedures for protecting confidentiality, and how to provide adequate security. Although more detailed information about these and other related issues is provided in chapters II and III, some comments are included here to ensure planners are sensitized to the general issues.



## DATA MANAGEMENT

The daily operation of the registry will require policies that address: data acquisition, timeliness of data entry, data quality, error correction, and consolidation of multiple records into a single record per individual. User education and training will be necessary on all these issues.

The importance of good planning cannot be over emphasized. The registry will house both demographic data and medical/health data. Potential sources of data include vital records, such as birth certificates, death certificates, adoption records, immunization records. Other sources may be provider billing systems and other databases such as those of Women, Infants and Children (WIC) clinics, or Aid to Families with Dependent Children (AFDC) offices. Policies are needed that specify whether data will be entered by providers or the registry; who will be responsible for making sure the data given and received are accurate; who has the authority to enter, alter, or delete records; and how duplicate records will be identified and removed. If the registry will cross jurisdictional lines, policies are needed for working with the various entities that may have governing power. Examples of approaches to handling some data-related responsibilities follow.

In **Arizona** the registry is being built with a distributed data base. In so doing, each provider has an incentive to ensure the quality of that portion of the data base that will represent their client records. Entry of immunization data is the provider's responsibility. However, the state provides the tools to upload the data into a state registry that maintains a copy of the immunization data and merges records of individuals seen by multiple providers. Such updated records will be returned to providers.

In **Camden, New Jersey** some providers will submit data to the registry through a service organization responsible for collecting paper records from the providers' offices and accomplishing the data entry.

In **Nashville, Tennessee and Savannah, Georgia** the health departments initially sent clerks into providers' offices to enter historical data, but found this service too expensive. Providers are now expected to have their own staff enter data into the central registry that will monitor quality. The actual registries are initially populated from birth certificates.

In **Rhode Island** a number of programs needed data, so the state is planning a single registry system designed to accommodate all their data needs. Immunization, Newborn Hearing Screening, WIC, Early Intervention,

Newborn Laboratory Screening, Lead Screening, Newborn Risk Evaluation and Home Visitation/Risk Response will all be included. The state's health department will be responsible for data accuracy and completeness.

In **Snohomish County, Washington**, in addition to records obtained from birth certificates and data entry by clinics, the very large data base of a major HMO has been downloaded into the registry where consolidation of records was undertaken.

## **CONFIDENTIALITY AND SECURITY**

**Confidentiality issues** will be raised in many contexts as the organizations and residents of the community become involved in discussions about establishment of an immunization registry. Areas that should be considered and that require **clear policies and procedures are delineated in detail in Chapter II**. In summary, every registry should have a written confidentiality policy that addresses the following issues:

- o defining for their community the meaning of the terms:
  - Immunization registry
  - Immunization-related data
  - Privacy
  - Confidentiality
  - Data security
- o How privacy and consent will be handled at the time a record is initiated
- o Who holds data and what their confidentiality responsibilities are
- o Who has access to data and for what purposes
- o How information will be protected against unauthorized disclosure
- o Penalties for unauthorized disclosures

**Security** procedures that are established for the computer and telecommunications systems and the registry database system are an important part of the efforts to protect privacy and confidentiality. While the absolute security of any computer database cannot be assured,

immunization registries will be responsible for taking reasonable steps to provide security. This requires well thought-out policies and procedures as well as consideration of secure technology. Different technologic approaches have various strengths or weaknesses where security is concerned. Adequate resources need to be budgeted. **These issues are discussed in greater detail in Chapter III.** In summary: Every registry should have a written security policy and effective procedures that address the following issues:

- o Identification of the information that needs protecting
- o Identification of the threats to information security based on system design
- o Identification of solutions to mitigate the threats

## **PLANNING THE TECHNOLOGY**

Setting the scope and objectives of the registry are the basis of selecting technological approaches to operation. The planning process must include the purposeful bringing together of public health program staff and technology experts as a team. They must develop a mutual understanding of the registry needs as well as the technological capabilities available, in order to intelligently select from the various options that exist.

**Chapter III addresses in more detail each of the following steps that should be followed:**

- o Setting the functional requirements of the system
- o Identifying the data that will be needed to support those functions
- o Selecting a system architecture that will meet the needs of providers
- o Ensuring that protocols for record exchange are compatible with standards
- o Designing in security features at all levels of the system
- o Ensuring that immunization needs assessment algorithms are developed that will adapt to change

## FINANCING THE REGISTRY

Ideally, development of a registry should be driven by an intent to comprehensively implement the initial vision. To the extent possible, adequate resources should be identified beforehand. The alternative is to identify currently available resources and design a registry that can be implemented using them. This alternative approach carries the risk of being too limited in scope, and failing to make a meaningful impact. In practice, most registries will need to find a balance between an original vision and the resources that may realistically be obtained. Simultaneously, additional resources should be sought in order to maximize the registry's ultimate accomplishments.

A proposed budget based on the different feasible options identified, will help in determining the relationship between services that can be provided to users, and funding needed. As mentioned earlier in this chapter, resource considerations should include initial development, implementation, long-term operation, maintenance, and upgrading to new technologies. Write a budget that includes the costs of personnel, equipment, software, contracts, supplies, training, office operation, phone, and other projected operational costs. Cost information from comparable systems and information about possible financial support, short- or long-term financing projections for the registry can be prepared. Some state registries, such as Ohio's Immunization Information System and The New Mexico State Immunization Registry, have been supported entirely by federal and/or state grants. Examples of other approaches follow.

In **Philadelphia** the All Kids Count Project received funding for five years from a Robert Wood Johnson (RWJ) Foundation grant. CDC has provided funding for personnel and software developer support through a Childhood Immunization Grant. The Mercy Health Plan (MHP), currently the largest Medicaid managed care organization in Philadelphia, has agreed to provide a three-year grant for development and implementation of the registry, named the Kids Immunization Database/Tracking System (KIDS.) The William Penn Foundation and the Pew Charitable Trust Foundation have expressed a desire to support KIDS subsequent to the RWJ and MHP funding period.

In **Rochester, New York** HMOs have been included on the planning board of the registry, and are willing to contribute to sustain the registry, provided that registry information cannot be used to take their clients away.

In **San Diego County** funding from the Annie E. Casey Foundation grant will be supplemented by funding from the California State Health Department as well as a CDC immunization award. In addition, some providers are willing

to pay for reminder/recall services for their patients. HMOs pay \$1 to \$2 per child for such calls.

## **PROMOTING THE REGISTRY**

Promotion is part of an overall communications plan, that should include dealing with handling the media on a day-to-day basis, handling emergencies, and negative publicity. The Promotional Plan includes all of the following:

- o An explanation of the mission and objective(s) of the registry
- o A plan for delineating the community segments to be reached
- o A plan for listing the benefits the registry offers to the community
- o An analysis of the best methods and media for getting the message across to each community segment. Much of the research needed for this part of the plan will have been gathered in the analysis phase.

Promotion of the registry with additional providers demands careful attention. Prioritizing the order in which various types of providers will be added to the system depends on having set and met realistic expectations for service. Promising customers more than can be delivered will dampen new providers' enthusiasm to participate. Additionally, attention must be given to prospective new providers' budget cycles. They may need to purchase new equipment or software in order to participate and they may only be able to do so at the appropriate point in their budget process. The following steps are suggested:

### **Define the objectives of promotional activities**

Define exactly what is to be accomplished by the promotional plan. One example might be to increase understanding among private providers of the ways the registry will improve the quality or efficiency of health care delivery in provider-owned clinics. An additional objectives may be to encourage certain sections of the community to include their children in the registry. New issues may arise as the registry develops and experience is gained.

### **Select the community segments to be targeted**

Identify as much information as possible about the different segments of the community

within the registry's catchment area. Basic information should include demographic data, such as age, sex, race/ethnicity, income, education, number of and ages of children. In addition, information on the attitudes and beliefs of each segment will be helpful. Prioritize the concerns for each segment and concentrate on the most important ones. Demographic data will help in identifying the most effective means (print, electronic, one-on-one contact) of communicating with each segment of the community. This information will also help in choosing the specific media to use. For example, many urban Hispanics rely on Spanish-language radio for community news and information about products and services. Therefore a Spanish-language radio station may be the best choice for reaching that community segment.

### **Specify the benefits to each community segment**

Determine the benefits the registry will offer each community segment in the catchment area. Pay attention to attitudes, beliefs, and concerns expressed by those segments. The benefits provided by the registry for their children are the answer to their concerns and become the message for each community segment.

### **Set goals**

Identify goals or specific reactions desired from each community segment in response to the promotional message, keeping in mind the overall goal. Recognize that there is no single correct way to proceed that will be effective in all communities.

### **Evaluating the promotional campaign**

An evaluation of each promotional event should be built into the plan to determine what works best. This may include conducting pre- and post-campaign surveys of opinions and attitudes within targeted groups. See the appendix for further information.

## **Section 4: SUMMARY OF 30 KEY ACTION STEPS: PLANNING**

### **Needs assessment**

1. Identify major challenges to immunizations for the community to be served and define the structure of the health care delivery system(s) in the catchment area.
2. Obtain input through town meetings and focus groups with physicians, nurses, community groups, and appropriate others.
3. Collect data “up front” to demonstrate the immunization problem to others who must “buy in” to the registry concept. Use tools such as Clinical Assessment Software Application (CASA) to assess immunization coverage provided by individual clinics.
4. Summarize information and opinions obtained in advance of meetings planned to build support for the registry. Plan how to make that information available to interested parties such as the governor, mayor, county manager, legislators, provider groups, and to payers such as employers and insurers. This information is critical in demonstrating to them why they have a stake in an immunization registry.

### **Looking at technology**

5. Identify current health information systems in the registry area. Determine if the registry can interface with any of these.
6. If necessary, identify a partner to provide technical expertise. Sources might include a university, government computer systems support office, community business, or a paid consultant.
7. Survey providers about their computer equipment and future plans for investment in information technology.
8. Contact possible vendors and planned registry users for information about available systems and how they perform.
9. Consider the pros and cons of alternative approaches based on experiences of others, particularly as they impact on telecommunications with private providers

## **Costs and Support**

10. Prioritize the steps in setting up the registry and set realistic goals and objectives, time lines, and staffing levels needed for planning and implementation.
11. Obtain information on costs of setting up a registry in areas comparable to yours.
12. Obtain or formulate a cost analysis for a registry comparable to yours.
13. Seek long-term support from potential users. Relate their support to the services they will receive in return and potential improvements in quality or efficiency of the care they will provide their clients. Articulate to them how administrative tasks that they perform, such as preparing certificates for school entry, will be streamlined.
14. Contact private and public foundations, government, businesses, and other community resources that might provide financial support. If soliciting donor support, remember that historically 80% of donations to initially establish community projects have come from a single individual donor in that community.
15. Seek in-kind contributions and volunteers to help with promotions, computer programming, printing, and other activities.

## **Forming Community Partnerships and an Advisory Board**

16. Examine existing, established community programs and initiatives to determine if they relate to the registry and might assist in its implementation.
17. Determine under whose auspices critical meetings will be held to establish advisory and governing bodies. Invitations should be sent out under the letterhead of that organization or individual. Having a highly influential person in the community bring stakeholders to the planning table may make the difference as to who will attend and become future partners.

## **Establishing governance and the scope of the registry**

18. Develop a draft mission statement and proposed clear goals and objectives for the registry. Obtain a consensus on these among the community partners. Involve



technical and budgetary experts to ensure the scope of the project is in keeping with available resources.

19. Establish special interest committees to handle promotion, secure financing, and design evaluation tools. Reach agreement on specific tasks to be undertaken by each participant.
20. Develop a formal plan at the outset to evaluate the success of the registry in terms of processes and outcomes. Identify what should be monitored, what data sources can be used or must be established, and who will be responsible for doing the monitoring.

### **Data management**

21. Establish lines of communications with medical data sources such as vital statistics registrars, medical insurance claims processors, WIC program, or other entities that maintain immunization data bases. Determine the scope of their work and their potential interests and capabilities to share data.
22. Determine whether special agreements must be made between other agencies and the registry. Determine what time must be allowed for negotiating agreements and making procedural and technical arrangements for data sharing.
23. Determine the most realistic approaches to populating the data base. Decide whether it is feasible to obtain existing historical data of high quality, or if it is better to start the registry with new data, verified for accuracy at its source.
24. Encourage providers to conscientiously enter data and ensure its accuracy.
25. Include the issue of data quality in your user training plan that will be needed for providers and their staff.
26. Develop formal policies and procedures relating to confidentiality and security.

### **Promoting the registry**

27. Determine the intended objectives for promotional activities. If possible, work with a consultant to incorporate promotional activities into a broad communications plan.
28. Prioritize the segments of the community to be targeted by the promotional campaign

and choose the best method(s) and media for each segment.

29. Create a symbol, logo or mascot to embody your message and keep the overall goal in the public's eye.
30. Design a survey or other instrument to test the knowledge, opinions, and attitudes of target audiences before and after the promotional campaign.

## **APPENDIX I-1**

### **Example of a promotional plan.**

#### **Objectives for different segments of the community**

##### **General public**

*Concern:* How vaccine-preventable diseases affect the entire community.

*Message:* The registry will provide a public health benefit in reducing disease susceptibility and the risk of outbreaks.

*Desired outcome:* The public will support immunization activities and the registry.

##### **Patient community**

*Concerns:* A lack of trust, on the part of some, in the government's motives for creating a registry; a view that the government has no legitimate interest in compelling segments of the population to conform to its concept of ideal health care; concerns that data will be used for other than stated purposes. Concerns on the part of the public about confidentiality of personal medical information and fear of secondary disclosure."

*Message:* The benefits of participating in the registry are: Healthy, immunized children; less difficulty or time lost when applying for other government benefits such as WIC or AFDC; easy access to child's records for school, day care, sports, etc. Confidentiality will be strictly enforced, and will involve community representation for "oversight."

*Desired outcome:* Parents will consent to participate; will respond to reminders/recall; will keep their appointments; and serve as lay health workers and volunteers.

##### **Health care community**

*Concerns:* Resentment of government intrusion into their medical practice; fears of "patient stealing" and having possibly low coverage rates publicized; fear of data being used for punitive/compliance purposes by MCOs, health departments, and/or other agencies; fear of being unable to overcome

technological barriers; lack of trust in data quality/integrity; concern about costs of modifying systems (hardware/software) to provide information to the registry; concern about staff time required for participation; confidentiality concerns; and fear of liability involving release of information and possible secondary disclosure.

*Message:* The benefits of participating in the registry are: adequate data to know what shots are needed; improvement in coverage rates; ease of providing immunization records to parents; increase in the number of children who will return to care and receive immunizations as well as other primary care services, increasing revenues; and participation in the registry should tend to minimize intrusion of field auditors in the office performing assessments.

*Desired outcome:* Providers will participate in the registry; promote the concept with their peers and patients; send immunization reminders to patients; possibly modify billing system and provider registry systems; share costs; minimize missed immunization opportunities; and provide assessments and Quality Assessment data.

### **Business community**

*Concern:* How much will it cost?

*Message:* Better immunized children mean parents have fewer unscheduled absences from work; improves corporate status in the community and promotes their community mission; and advertises the company while promoting a health message.

*Desired outcome:* Businesses will provide financial support, promotion and advertising; promote immunization among their employees; negotiate for expanded health insurance coverage for their employees to include coverage for immunizations; give their employees scheduled time off to take their kids for immunizations and well-child care.

## **APPENDIX I-2**

### **American Academy of Pediatrics (AAP) Policy on the Development of Immunization Tracking Systems (ITS)\***

It is the policy of the AAP, in its role as advocate for children, to support public and private cooperation in the development of immunization tracking systems (ITS) insofar as they benefit children. All ITS as they are developed:

- o should clearly articulate their goals and desired outcomes, including goals of documenting immunization status and the mechanics of immunization, increasing rates of immunization, decreasing cost of immunization, and facilitating immunization opportunities.
- o must accurately document each child's current immunization status.
- o must preserve the child's and the health care provider's right to privacy.
- o should ensure that data will be available to health care providers 24 hours a day, 7 days a week, so that no opportunity to immunize will be missed.
- o should ensure that data will not be used for sanctions against health care providers.
- o must ensure that data input and access mechanisms enable providers to easily supply and access data without having to purchase specialized hardware or expensive software. Input and access software mechanisms need easily to enable all providers to supply data to and retrieve data from the ITS.
- o should entitle health care providers to be reimbursed for the cost of providing data to ITS.
- o must ensure that data reflecting evidence of incomplete immunizations will not be used to deny a child access to care or eligibility for benefits by any insurance plan.
- o must be studied and/or evaluated to determine their effectiveness in increasing immunization rates and decreasing costs. If such systems do not fulfill these goals, they should be eliminated.
- o should be a collaboration between public and private initiatives with the ability to link to larger data systems, e.g., community health information networks or CHINS, etc.

Approved by the Board of Directors on February 24, 1996.

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